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STUDY OF CO-PRODUCTION IN SERVICES FOR PEOPLE WITH DISABILITIES

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epr
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EASY-TO-READ SUMMARY

ABOUT THIS DOCUMENT

The European Platform for Rehabilitation is a network of organisations that provide services to people with disabilities and other people.
For short we call it EPR.

This document tells about how EPR members work together with people using their services. This is called co-production.

Ten EPR members told us about their work.

They are:
- The Marie Homes – Denmark
- Centre de Readaptation de Mulhouse – France
- Josefsheim Bigge – Germany
- Theotokos Foundation – Greece
- Rehab Group – Ireland
- Heliomare – Netherlands
- Fundação AFID Diferença – Portugal
- University Rehabilitation Institute – Slovenia
- Residencia Fundación Intras Toro – Spain
- ONCE Foundadion – Spain

ABOUT CO-PRODUCTION

Co-production means that people who use services and people who run services work together as equals. Being equal means that nobody is more important than anyone else.

People who use services know best what services they want.

Co-production gives people more choice and control over services.

This means that they have a say about how services are planned and delivered. They also have a say about whether services are good.

Co-production makes services better for people using services.

WHAT WE HAVE FOUND

Some organisations work together with people using their services to develop individual plans for care and support.

Individual plans describe what the person wants to achieve and what support they need from the organisation to achieve it.

This gives people a say about their individual support.

Other organisations involve people in decisions about services they provide.
People can have a say about what they want the services to do and how.

All organisations want to continue to work together with people using their services in the future.

There are things that need to happen to make it easier for organisations and people to work together as equals.

WHAT GOVERNMENTS AND ORGANISATIONS NEED TO DO TO SUPPORT CO-PRODUCTION

- Understand that people with disabilities have the same right to participate in decision-making as everyone else.

- Change the laws restricting the right of people with disabilities to make their own decisions. Adopt laws and policies promoting involvement of people with disabilities in planning and delivery of services.

- Make sure that people with disabilities have the support they need to participate in decision-making as equals. This could include peer support, advocacy, training and personal assistance.

- Make sure that everything they do is accessible to everyone. This could include meetings, events and information.

- Make sure that there is enough money and support for co-production.

- Provide training and support to people working in governments and organisations to understand co-production and to put it into practice.

1. INTRODUCTION

A. The European Platform for Rehabilitation (EPR)

EPR is the network of service providers to people with disabilities committed to excellence and innovation through mutual learning. Its vision is that EPR contributes to a society where every person with a disability or other disadvantages have access to the highest quality services that create equal opportunities and independent participation in society.

EPR activities go beyond traditional mutual learning exchanges. EPR members co-create and pilot innovative products, tools and methods to better meet the needs of clients, employers and funders. Professionals from EPR members gather to benchmark and analyse effectiveness in service provision over time; improving quality of services and quality of life for clients, as well as positively impacting their daily work experience. Through membership of the European Platform for Rehabilitation, organisations are better equipped to be competitive in a changing market environment.

EPR offers numerous opportunities to network with leading service providers from across Europe. EPR members are committed to high quality service delivery in the fields of vocational education and training, employment reintegration, medical rehabilitation and social care. In addition to the experienced secretariat, EPR initiatives are supported and facilitated by renowned experts in these fields.

Through its public affairs activities, EPR enables service providers to contribute to the social and disability debate and to the strengthening of the social service sector. In addition, EPR facilitates access to EU funding through project development support, partner matching and training sessions.

B. Aims and purpose of the study

This study is part of a series of reports, published by EPR since 2014, that aim to provide evidence of trends and developments in delivery of services to people with disabilities. In 2014, the focus was on transition services for young people with disabilities (McFarlane, 2014), in 2015 – on services supporting the inclusion of people with disabilities in mainstream environments (Pinto and Pinto, 2015). This year, the study looks at practices of EPR members of co-production in service delivery, with a focus on services for people with disabilities

This study can be a useful resource for service providers, people with disabilities and organisations of people with disabilities, policy and decision makers at local, regional and national level, and the European Union institutions.

The aims of the study are:

- To raise awareness of co-production as an approach to service delivery, which respects the right of people with disabilities to be involved in decisions affecting them.
- To present examples of involvement of people with disabilities in service planning and delivery.
- To provide recommendations to inform the development of future initiatives using co-productive approaches.
- To point out changes in legislation, policies and funding needed to support the implementation of co-production.

The study has been drafted based on the inputs from EPR member organisations and with financial support of the European Commission under the Programme for Employment and Social Innovation, "EaSi" (2014–2020).

2. WHAT IS CO-PRODUCTION?

For the purpose of the present study, 'co-production' is understood to mean equal partnership and collaboration between service providers and people using services. Co-production is about recognising that people who use services are experts in their own right, rather than passive recipients of care ('clients', 'service users'), and about involving them in the shaping of services. This requires a shift of power and control from service providers towards people using services. Instead of having services designed and delivered for people with disabilities, they are designed and delivered with them.

The table below illustrates that co-production occurs when the expertise of professionals and of people using services is combined.

	Professionals as sole service planners	Service user and/ or community as co-planners	No professional input into service planning
Professionals as sole service deliverer	Traditional professional service provision	Traditional professional service provision with users and communities involved in planning and design	
Professionals and users/communities as co-deliverers	User co-delivery of professionally designed services	**Full user/professional co-production**	User/community co-delivery of services with professionals, with little formal planning or design
Users/communities as sole deliverers	User/community co-delivery of services with professionals, with little formal planning or design	User/community delivery of co-planned or co-designed services	Traditional self-organized community provision

Source: Bovaird, 2007

The key principles of co-production include:

- **Shared power:** The power to decide about and shape services is shared between service providers and people using services, and the division between them ('us' and 'them' culture) is blurred. This results in the development of new, innovative ways for service design and delivery.
- **Equal participation:** The experience and skills of everyone involved in the process of co-production are equally valued and used. Measures are taken to ensure that everyone, regardless of their place of residence (in a residential institution or living in the community), type and degree of impairment, gender, race, class or sexual orientation, can participate on equal terms.
- **Reciprocity:** People using services work in reciprocal relationships with professionals and with each other, where they have mutual responsibilities and expectations (Boyle et al., 2010). The engagement of people in co-production is respected and they receive something back for what they do.

Some authors distinguish between different types or levels of co-production, based on whether the focus is on the individual or services (Hampson et al., 2013). At the level of individual, co-production refers to the planning of personalised support and care; at the level of service (or community), it is about involvement in the planning and design of services on the whole. More often, the term 'co-production' is used to refer to involvement at the level of services and terms like 'person-centred' (or 'personalisation') are used for individual level cooperation. What is important in both cases is the stress on the involvement of people with disabilities in the decision-making about services.

A distinction is often made between co-production and participation, where the latter refers to limited involvement of people using services through consultation. Consultation usually means that people are only approached to express their views at the beginning of the process and then marginalised and disengaged, while co-production requires involvement throughout the whole process and equal partnership.
The introduction of a co-production approach in the work of an organisation is a process, which requires a number of changes to be made in the culture, policies, practices and structures of the organisation.

Different organisations can be at a different stage of development of co-production, ranging from basic, sometimes fairly tokenistic, user involvement, to advanced (transformative). At the basic stage, people using services are listened to, for example through consultation events, and they have some, although limited, say about how the service is developed and delivered. At the advanced stage, co-production is integrated into all levels of the organisation (from senior management to frontline staff) and the involvement of users is a regular practice, rather than a one-off event.[1]

Co-production approach can be applied at all stages of service delivery - in the planning, design, delivery and evaluation of services. While the present study focuses on the provision of support services to people with disabilities, co-production can be used in different areas and types of services.

THE CASE FOR CO-PRODUCTION

The arguments for co-production come from both the human rights and efficiency perspective. There are strong links between co-production and human rights. Some of the key principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), such as involvement of people with disabilities, respect for dignity, autonomy and independence, underpin the principles of co-production.

The requirement to consult *and* actively involve people with disabilities, including children with disabilities, in the decision-making on issues that concern them, lies at the heart of the CRPD (article 5(3), reflecting the disability movement's slogan 'nothing about us without us'. In line with this principle, the involvement of users of services as equal partners in decisions about design and delivery of services is a defining characteristic of co-production.

The Convention also sets out the right of people with disabilities to live independently, which includes being able to exercise 'freedom of choice and control over decisions affecting one's life' (OHCHR, 2014: para 13). In co-production, the transfer of power from service providers involves enabling people using services to have more choice and control over the design, delivery and evaluation of services. Thus co-production is seen as 'core to choice and control' and as a resource that 'can help make Independent Living a reality for all' (ENIL, 2013).

Together with this, there is growing evidence that co-production can lead to more efficient service delivery – because it contributes to more effective and sustainable outcomes, helps people achieve better outcomes than most services do, helps prevent problems, improves individual well-being, contributes to increased resilience and supports better use of scarce resources. In addition, the Organisation for Economic Co-operation and Development (OECD, 2011) underlines the potential of co-production to increase service effectiveness, tackle service failures, enhance societal as well as individual well-being, improve democratic governance and build public trust, strengthen communities and build social capital.

[1] A number of self-reflection tools have been developed allowing organisations and individuals to assess how they cooperate with people using their services and to identify areas for improvement. See, for example, Clark and Nicoll, 2011 and NESTA, NEF, Innovation Unit, 2012.

3. FINDINGS FROM THE STUDY

This chapter provides a summary of the responses of EPR members that took part in the study. It follows the structure of the study protocol, consisting of three main sections: description of the project/programme, results and reflections, and information about the context.

The analysis is based solely on the information provided in the responses. Each organisation has decided what practice (project/programme) to submit based on the definition of co-production, set out in the study (where it is defined as equal partnership between people using services and service providers). The study was open to practices of involvement of people with disabilities in the design and delivery of services, without restrictions related to the nature of involvement (for example, in the planning of individual support or in the design and delivery of whole services), the stage of development of co-production (basic or advanced), the area (for example, education, employment, housing, and social care) or length (short- or long-term).

A total of 10 responses were received from 9 countries. The table below contains a list of all practices by country and organisation.

Country	Organisation	Practice
Denmark	'Aase Marie' in The Marie Homes	Aase Marie – housing and support of people with dual diagnoses (drug abuse and mental illness)
France	Centre de Readaptation de Mulhouse (CRM)	70th Anniversary of the CRM
Germany	Josefsheim Bigge	We Empower u**S bH** - Better career opportunities for people with **S**pina **b**ifida and **H**ydrocephalus in Europe
Greece	Theotokos Foundation	Peer Advocacy Group
Ireland	Rehab Group	Rehab's Advocacy and Representative Structures
Netherlands	Heliomare	Individual Transition Plan
Portugal	Fundação AFID Diferença	Inclusion Group, Occupational Activities Centre-Individual Plan for Development (PDI), input in activities.
Republic of Slovenia	University Rehabilitation Institute	Use of the individual rehabilitation plan in vocational/occupational rehabilitation
Spain	Residencia Fundación Intras Toro	Asambleas colaborativas (Collaborative assemblies)
Spain	ONCE Foundation	Trainers Paralímpicos (Paralympic Trainers – Life Trainers)

SECTION I
DESCRIPTION OF THE PROJECT/PROGRAMME

This section looks at the goals of the practices, their timeframe, location and activities, including activities aimed to support people with disabilities and staff members to engage meaningfully in the co-production process.

It provides brief information about whether and how existing legislation and policies at local, regional or national level promote and support co-production in social care. It also contains some recommendations for legislative and policy measures to encourage and support co-production, which are developed further in the conclusions.

CONTEXT

Many organisations point out that their national legislation, usually social care legislation, recognizes the right of people with disabilities to participate in decision-making, which is at the heart of co-production. One of the recommendations here is related to the need for more frequent monitoring and supervision of the implementation of legislation by the relevant institutions, in order to ensure that people with disabilities are really involved (AFID).

Other examples of relevant national-level legislation supporting involvement include laws on assisted decision-making (Ireland) and participation (Germany). The UN Convention on the Rights of Persons with Disabilities, as the key document setting out the rights of people with disabilities, is also mentioned by some organisations, although it is recognised that its ratification is only a first step towards changing the situation (Theotokos).

GOALS

Four of the practices are focused on enabling people using services to achieve greater influence on the development, implementation and/or evaluation of their individual plans. These are practices by Marie Homes, University Rehabilitation Institute (URI), Fundação AFID Diferença[2] (AFID) and Heliomare. Their goals include encouraging motivation and participation, promoting autonomy of people using services, and fighting exclusion.

[2] AFID has also included examples of input from people using services in activities.

A number of organisations have sought to ensure greater influence and/or involvement of people in service delivery by supporting the establishment and the functioning of user-led groups – Residencia Fundación Intras Toro (INTRAS), Theotokos Foundation, and Rehab Group. The specific goals are related to supporting self-advocacy, the development of advocacy and self-advocacy skills, empowerment, establishment and development of horizontal relationships within the service, and participation in decision-making.

Two of the practices are focused on cooperation with people with disabilities in the planning and implementation of short-time projects or one-off activities. Centre de Readaptation de Mulhouse has cooperated with people using its services and Josefsheim Bigge has worked in partnership with self-help associations and people with disabilities outside their services.

Finally, ONCE Foundation has described a business partnership in which people with disabilities provide a service, managed by ONCE, taking part in decision-making related to certain aspects of the business. The aim is to provide career opportunities and promote entrepreneurship.

TIMEFRAME

Some of the practices have started with the launch of the service with which they are associated, for example, with the opening of the housing programme Aase Marie at the Marie Homes or of the place of residence Toro, INTRAS. Others have been developed at a later stage, for example, the advocacy groups in Theotokos and Rehab Group. Regardless of how long the practice has been in existence, all organisations intend to continue to involve people with disabilities in the development and implementation of projects and/or provision of services in the future.

All practices where a specified start date is mentioned (6 practices), are from the last 7 years – between 2009 and 2016. The emergence of such practices in the recent years could be linked, among other things, to the increased stress on involving people with disabilities in decision-making, following the adoption of the UN CRPD (now ratified by all countries represented in this study, except Ireland) and the understanding that involvement of people using services leads to better quality and outcomes.

LOCATION

The large majority of practices are local - based in one of the locations where organisations provide services (for example, a school, a residential setting or a rehabilitation centre in a particular town or municipality), although services are usually open to people from other locations. There is one national and one international-level practice. For example, Rehab Group has supported the setting up of advocacy committees in every location where the organisation provides services, thus achieving a national coverage. Josefsheim Bigge brought the cooperation to European level, working in partnership with service providers, people with disabilities and organisations of people with disabilities from five European countries.

CO-PRODUCED ACTIVITIES

This section provides more details about the following how people with disabilities are involved in the design, delivery and evaluation of services and projects, the integration of the practices in the core service of the organisation, and the development of activities supporting people with disabilities and staff members to work together.

Most of the practices are about involvement in decision-making – either about individual care and support or about the service as a whole. Several organisations mention that people with disabilities have also been involved in the delivery of services or the implementation of projects (INTRAS, CRM, Josefsheim Bigge).

The practices that concern the use of person-centred approaches in the development of individual plans (Heliomare, URI, the Marie Homes and AFID) involve people using services working together with a staff member or a team to define their individual goal/s, to identify activities, methods and techniques for achieving the goal/s, to decide about the timeframe and responsibilities, to monitor and evaluate the progress and to make revisions.

All other practices involve setting up groups of people with disabilities, either using the services of the organisation or external people, to meet regularly make decisionns about issues concerning them. Some of these groups are user-led, which means that the agenda is set by the people using services, who also chair and run the

meetings and make decisions (Rehab Group, Theotokos, INTRAS). Members of the 'user groups' also take part in meetings of the leadership and/or the staff. Where the number of users is too big to allow for a group to work effectively, representatives have been elected by people using services. Other groups consist of people with disabilities and representatives of the organisation taking joint decisions – about the organisation of an event (CRM), the business model of the service (ONCE) or the planning, implementation and evaluation of a project (Josefsheim Bigge).

Integration of co-production within the core programme/service

Some of the responses provide interesting examples of involvement, which is structurally integrated into the organisation's core service/s through the building of representative advocacy groups at different levels of the organisation – local, regional and national level, in the case of Rehab Group and group, departmental and organisational level, in the case of Theotokos. The practice of Josefsheim Bigge demonstrates how involvement can also be integrated within a short-term project by ensuring that 1) people with disabilities have been involved in the development of the project, as well as in its implementation and that 2) the project management and implementation structures include people with disabilities.

Encouraging and supporting staff and users to engage in co-production

Most practices involve the provision of some kind of support to people using services to participate in decision-making. It could take the form of a 'mentor', 'case manager', or 'contact person' assisting the person in the development and implementation of their individual plan (Heliomare, Marie Homes, URI), or 'supervisors' or 'advocacy team', supporting the work of the user-led groups (Rehab Group and Theotokos). Additional financial resources have also been allocated to cover extra costs and allow for full cooperation (Josefsheim Bigge).

With regard to the ways to encourage professionals to cooperate with people using services, many practices refer to the values and philosophy of the organisation, related to empowerment, autonomy or inclusion (INTRAS, The Marie Homes, URI). Some point out the importance of organising specific activities (for example, trainings, support and facilitation) for staff, in order to ensure they understand the importance of involving people using services in decision-making (Rehab Group, Josefsheim Bigge). The availability of clear and well documented description of the method and tools used is also seen as key (Aase Marie, URI).

WHY THIS IS A CO-PRODUCTION

This section presents organisations' own accounts of why their practice can be regarded as co-production. It shows their understanding of what co-production is and what its defining characteristics are.

The key theme is related to people using services having more choice and control. It has two aspects. The first one is about people having more choice and control over their individual support – for example, being able to choose their own goals (Heliomare). This involves being able to reject proposals from staff that do not fit with their ideas as well as staff respecting their decisions (The Marie Homes) and contributing to the planning of activities (URI). The second is about people having choice and control over the service or project – for example, participating in decision-making about issues affecting the organisation or the project (Rehab Group, Josefsheim Bigge, ONCE), deciding about issues that affect their everyday life (INTRAS) and getting involved in the implementation of activities proposed by them (CRM, INTRAS, AFID). Another common theme is related to giving a voice to people using services – for example, to express their opinion about the service, to raise concerns and make proposals, to highlight issues of importance to them (AFID, Theotokos).

SECTION II
RESULTS AND REFLECTIONS

This section looks at the outcomes of the initiatives, the challenges and lessons learned from their implementation, and plans for their future development.

Outcomes and achievements

Various outcomes of the cooperation between professionals and people using services have been identified by the organisations, including related to the people, staff, relationships or the service as a whole. A number of organisations have observed increased satisfaction of people using services and staff (AFID, CRM) and better relationships between staff and members (INTRAS), which is also reflected in less violence in the residents' everyday life, fewer work-related injuries and low percentage of sick leave amongst the staff (The Marie Homes). Others point out the increased commitment of people with disabilities to the initiative and their willingness to engage in common projects (ONCE, INTRAS). The development of knowledge and skills (such as social and communication skills and self-advocacy skills) and the increased confidence and self-esteem of people with disabilities are also mentioned (Theotokos).

Another key outcome, reported by most organisations, is related to people using services having impact on the way the service or the project is planned, organised and/or delivered. In the case of Rehab Group, this influence has been extended to include 1) the organisation as a whole, for example, through the involvement of people using services in the development of the company policies and strategic plan and 2) the development of national policies, through engagement in external advocacy.

Challenges

The organisations have faced a number of challenges in seeking to ensure meaningful involvement of people with disabilities and to build collaborative relationships. An important challenge, mentioned in some of the practices dealing with individual plans, is related to existing unequal power relations, where people using services are at a disadvantage – for example, they have limited control over the planning process (Heliomare) or experience pressure to accept a certain vision of their desired future (Marie Homes). In the case of Aase Marie at the Marie Homes, this pressure comes from the municipality, which covers most of the costs of the residents and also sets some of the goals for their development (although residents' approval of the goals included in their individual plans is required).

Another key challenge comes from the way co-production is integrated within the organisation. It can be difficult to ensure that people with disabilities have the support they need to participate meaningfully, when co-production is not seen as something that all staff members are engaged with, but as a responsibility of a few people. (Theotokos).

There are also challenges related to the process of involvement, such as difficulties finding satisfactory solutions for everyone involved (Theotokos) or finding suitable time for meetings for both staff and people with disabilities engaged in the co-production process (Josefsheim Bigge). It is interesting to note that the difficulty faced by Josefsheim Bigge, according to their own account, is related to the different positions of the staff and the representatives of people with disabilities in the project. Whereas the staff are paid, people with disabilities are volunteers with external job commitments who do not receive compensation for their involvement. This has affected the preferences and availability for meetings and has had a negative impact on the possibility for more extensive engagement with the project.

A final challenge concerns the continuous and active engagement of people using services. The way it is manifested varies from practice to practice. It can be related to the difficulty of ensuring that people using services take part in the whole process – from decision-making to implementation (INTRAS) or keeping them actively engaged after leaving the service, where they are with the service for a short period of time (Rehab Group). The engagement of people using services can be negatively affected by most of the challenges mentioned above, such as limited control of people using services, the lack of reciprocity, the lack of engagement of staff, and also by funding, and the culture and values of the organisations.

Lessons learned

The organisations share a number of insights and lessons learned from their experience that can help overcome challenges and strengthen cooperation. With regard to professionals, one of the points highlighted is the need for them 'to be collaborative, not paternalistic', to 'orientate' rather than carry out (INTRAS). In other words, they need to adopt a new role, which requires sharing power with people using services and accepting their expertise. Several organisations stress the importance of organising discussions with and trainings for staff (Marie House, Josefsheim Bigge, Rehab Group). The importance of engaging people at all levels of the organisation is also mentioned. Ensuring that everyone in the organisation is 'aware of and positive to the inclusion of people with disabilities in all decision-making' has been found to greatly improve the opportunities of people with disabilities to take part in decision-making (Rehab Group). Choosing the right members of staff can also support the establishment of more equal relationships (Heliomare).

With regard to people using services, some organisations highlight their motivation and strong commitment as factors for the success of the initiative (ONCE, CRM). Other recommendations focus on the need to involve people as experts in as many activities as possible, while at the same time respecting their other commitments, not overloading them and compensating them for their work (Josefsheim Bigge). The importance of building communication and advocacy skills is also highlighted (Theotokos).

Future development

In general, organisations see the cooperation with people with disabilities and/or organisations of people with disabilities in decision-making as an on-going and expanding practice. Some of the directions for future development are related to improving the quality of involvement, for example, by addressing staff attitudes towards empowerment (Josefsheim Bigge), or to expanding cooperation by involving people with disabilities in higher level decision-making, for example, related to the management of the initiative (ONCE). Organisations supporting peer advocacy structures (Rehab Group and Theotokos) will seek to encourage the development of opportunities for collaboration outside the service they provide, which they expect to contribute to greater independence and autonomy of the advocacy groups and to increased influence on government policies.

Other directions for future development include building capacity of staff and using research and development (URI), and building on the experience from the practice in the future planning of activities (AFID).


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4. SELECTION OF CASE STUDIES

This chapter presents five case studies to provide readers more in depth information on the practices of EPR's members. Based on the information provided by the organisations in the study protocols, the five cases have been selected based on geographical representativity basis and are listed alphabetically by country. A full summary of all cases and the templates submitted are available on the EPR website (www.epr.eu)

CASE STUDY I

Name of the organisation: Marie Homes
Country: Denmark
Title of the practice: Aase Marie

'Aase Marie' is a housing programme, which opened in 2012. Its main goal is to create 'a good life' for people with dual diagnoses ('drug abuse and mental illness'), for example, through strengthening their social competences.

Each resident in 'Aase Marie' has an individual 'what-to-do plan', setting out the goals for their development. The plans are prepared with the support of a 'contact person' from the service. The municipality, which pays for most of residents' expenses, also sets goals (for example, use of money, shopping or cleaning). All goals in the plan, both short- and long-term, are approved by the resident. Their achievement is monitored 'in the local, digital 'Indikator'- programme'.

Through daily conversation and appreciative inquiry, the contact person helps the resident organise their everyday life and activities. The resident actively approves or declines every suggested activity and in this way she/ he gets to take responsibility for her/ his own life. Every resident is aware of her/ his opportunity of declining every suggestion from the staff. The staff respects the decisions of the resident as much as possible, having the well-being and respect of the resident as their top priority.

OUTCOMES AND ACHIEVEMENTS:

- Residents feel that they are recognised and accepted as equal individuals.
- Less violence in the residents' everyday life.
- Fewer work-related injuries and very low percentage of sick leave amongst the staff.

CASE STUDY 2

Name of the organisation: Josefsheim Bigge
Country: Germany
Title of the practice: We Empower u**S bH** - Better career opportunities for people with **S**pina **b**ifida and **H**ydrocephalus in Europe

The project "We Empower uS BH", developed by Josefsheim Bigge and ASBH (a national self-help association from Germany), is focused on vocational education for young people with Spina Bifida and Hydrocephalus. Implemented in the period 2010-2013, it brings together eight partner organisations – self-help associations and vocational training centres – from five European countries. The self-help associations are equal partners in the project. To ensure that they have the resources to cooperate fully, they received additional resources.

All project partners are involved in the development of support tools, aimed to improve the career opportunities for people with Spina Bifida and Hydrocephalus. Representatives of the self-help associations and people using the services of the other project partners, participate in all project meetings. They take on the role of an advisor and are involved in the development, testing and evaluation of the tools. One representative per self-help association is also a member of the project steering group, which plans, coordinates and evaluates the project. In addition, there is a committee of service users' at each partner, for information and monitoring.

One of the instruments, developed within the framework of the project, is the module 'Peer support'. Its basic idea is that all people with Spina Bifida and Hydrocephalus, involved in the project, should be given the opportunity to pass on their know-how and their experience to other people with disabilities. Training on peer support is organised and the project partners establish peer support services in their organisations.

OUTCOMES AND ACHIEVEMENTS:

A number of tools are developed, in consultation with people with Spina Bifida and Hydrocephalus, 'experts of their own affairs', and specialised staff. Seven instruments were developed, including: Guidelines for action and practical help in training and vocation, Empowerment and self-management of young persons with Spina Bifida and Hydrocephalus, Information, tips and hints for employers, Information for occupational guidance counsellors, Vocational biographies of people with disabilities, Promoting activities with the help of friends, colleagues and the social network, and Peer support training. All instruments support the empowerment of people with disabilities.

CASE STUDY 3

Name of the organisation: Theotokos Foundation
Country: Greece
Title of the practice: Peer Advocacy Group

In each of the seven Departments of Theotokos, there are 4 – 8 groups of students. All students from the age of 14 to 35 years participate in a process of peer advocacy. At the beginning of the academic year, each group elects a President. Then the Group Presidents elect the President and Vice President of their Department. The seven Department Presidents form the Students' Council.

The Group Presidents in each Department meet every three weeks to discuss students' needs and problems, supported by a Department Coordinator. The Students' Council comes together once per month, supported by two staff members; 'Supervisors of Peer Advocacy'. At the end of each year, the Students' Council participates in Theotokos' interdisciplinary meeting. There they present the year's outcomes and issues, followed by an open discussion. In the Students Council's closing session, members give feedback about all aspects of the peer advocacy process and suggest changes to improve the service.

Through the process of peer advocacy, students submit ideas, suggestions and complaints to the staff, in written or electronic form. Each request is recorded into the appropriate Quality System's procedure and answered. Students are encouraged and given the means to express and discuss all their ideas, problems and doubts about different aspects of their training programmes and the social life in Theotokos.

OUTCOMES AND ACHIEVEMENTS:

- Improved equipment to meet students' demands.
- Improved social and communications skills of students.
- Improved self-esteem and confidence of students.
- Improved self-advocacy skills, used both inside and outside of Theotokos' services.

CASE STUDY 4

Name of the organisation: Rehab Group
Country: Ireland
Title of the practice: Rehab's Advocacy and Representative Structures

Within Rehab's service, strong representative advocacy structures exist to support people who use services to self-advocate and to play a role in decision-making both inside and outside of Rehab's services. There is an Advocacy Committee in every Rehab service. Local, regional and national committees ensure that people in the services are represented at every level of the organisation. People with disabilities also take part in board level meetings. Every person who uses Rehab's services in Ireland is encouraged to play a role in these structures.

Advocacy Committees are led and chaired by people who use Rehab's services. Support is provided by a dedicated Advocacy Team, which is managed outside of the operational management. This contributes to a greater independence of the advocacy groups. The Advocacy Team provides a dedicated support service to ensure that people within services, and the staff who support them, receive the support, capacity building and facilitation to engage and participate meaningfully. Ongoing support is required for many people and the Advocacy Team works in partnership with local services to ensure that necessary training is provided to staff and members of advocacy committees alike.

The advocacy structures enable a strategic approach to participation in all consultation processes and planning processes within the organisation. It provides a framework within which the organisation can consult with and fully include people in decision making.

OUTCOMES AND ACHIEVEMENTS:

- Participation in Rehab's Strategic Planning Process: 131 people were supported to take part in consultation process to inform the strategic planning process.
- Participation in the development of Rehab's Group Policies: People using services were involved in providing feedback and ensuring that the implementation of policies is carried out in a way that is accessible to all.
- Comprehensive Employment Strategy Engagement: In 2015 the National Students Committee was invited by Minister of State for New Communities, Culture and Equality to discuss barriers to training and employment, experienced by students, in advance of the publication of a Comprehensive Employment Strategy.
- Participation in the consultation process to develop a National Cancer Strategy: 78 people were supported to take part in focus groups to gather feedback for the Rehab Group submission on the National Cancer Strategy.

CASE STUDY 5

Name of the organisation: Foundation INTRAS
Country: Spain
Title of the practice: Collaborative Assemblies - Residencia de Toro

Residencia de Toro is a residence 'for people with disabilities caused by prolonged and serious mental illness, from both genders'. Twice a week, residents and professionals take part in Collaborative Assemblies, in which residents have the leading role. They can express their feelings and make decision on issues affecting their everyday life in the Residencia de Toro. The main issues discussed usually include the weekly menu, cohabitating difficulties, household chores and leisure time. Participation is on voluntary basis.

The Collaborative Assemblies promote decision-making on issues affecting the everyday lives of the people living in the Residence. They aim to empower residents and include them in their own recovery process, transforming a passive role into an active one. The Collaborative Assemblies are spaces where residents can express themselves freely and in an autonomous way, without rejection or judgement. This activity promotes assertiveness, communication and social skills in the residents.

Horizontal relationships between staff and residents are the basis of this service, where professionals accompany residents along their recovery process. The final target is to encourage residents to make autonomous decisions about themselves, by discussing issues of their everyday life in the Residence.

OUTCOMES AND ACHIEVEMENTS:

- Residents who participate in Collaborative Assemblies feel better and more confident.
- Increased participation in proposed activities or common projects.
- Better relationships between residents and staff.

5. CONCLUSIONS AND RECOMMENDATIONS

This section presents concluding observations concerning the development of co-productive practices by EPR members, based on the analysis of ten study protocols. It highlights key points and concerns and suggests future directions for development of policies and practices.

Overall, the organisations that took part in the study are making targeted efforts to ensure greater involvement of people with disabilities in the development and delivery of services and projects and are planning to expand and improve this work in the future. Some of the organisations have shared examples of involvement in the planning of individual care and support, while others have looked at engagement at the level of the service or project. Inclusion, autonomy, and empowerment of people with disabilities are among the goals of most practices, regardless of whether the focus is on the individual or the service.

It is interesting to note that, in some cases, a stimulus for taking steps towards greater involvement was the need to address a specific problem within the service, such as the increase in the number of incidents of rude behaviour. Legislative and policy changes promoting participation of people with disabilities in decision-making – such as, the UN Convention on the Rights of Persons with Disabilities or relevant national-level laws and policies – have also made a difference.

Many of the practices demonstrate an awareness of the importance of supporting users to ensure genuine involvement. Additional resources have been allocated by some organisations to enable people with disabilities to participate meaningfully. Examples include staff member/s working with the person on the development of their individual plan or supporting the work of the advocacy groups, and additional funding to cover the initial costs associated with co-production. While few organisations mention explicitly that they have provided training and support to staff members to engage in co-production, many of the challenges and lessons learned stress how crucial such work is for the success of co-production.

The extent and depth of engagement (for example, how often people are involved, in which stage of the project development, at what level of decision-making, how much control they have) varies significantly between the practices. It is positive that some organisations have sought to ensure continuous involvement of people with disabilities in all stages of the practice described – from the development of the idea and the setting of the goals, throughout the implementation, to the evaluation of the results. Such a continuous involvement is what distinguishes co-production from consultation where people are usually excluded after their views have been heard during the initial stages of consultation.

There are also cases where user involvement is integrated at all levels of the organisation or the project. Together with this, some of the practices show that further efforts are required to move to a more advanced level of co-production.

A number of challenges to co-production have been identified by the organisations, including both internal challenges - related to staff, structure and practices – and external challenges – related to funding and relationships with donors, and engagement of people with disabilities (see Chapter II for more details). The analysis of the case studies has revealed other challenges concerning the culture of the organisation and its approach to involvement. For example, the language in some descriptions occasionally points towards existing division between staff and people using services ('us' and 'them), which can be a barrier to effective co-production. Another challenge is related to the danger of having the goal of co-production misplaced – for example, from participation in decision-making to building knowledge and skills. While the development of skills is essential for meaningful participation, the ultimate goal of co-production is sharing power and participating in decision-making.

Finally, the outcomes achieved by the organisations show the benefits of involving people when it comes to addressing problems in service delivery and delivering better quality services. There is also an example of how co-production can encourage political participation of people with disabilities by providing them with the skills, opportunities and support for political involvement.

RECOMMENDATIONS

This section contains specific recommendations aimed at service providers, policy-makers at national, regional and local level and the European Union. They draw on the challenges and lessons learned identified by EPR members which took part in the survey, and suggest areas for future development of legislation, policies and initiatives that can contribute to strengthening and expanding the use co-production as an approach to service planning, delivery and evaluation.

A. Rights-based approach

It is vital that all the stakeholders involved in co-production have a good understanding of the social model of disability, which underlines that the barriers in the environment – economic, social, cultural and political – restrict participation of people with disabilities. This will help ensure that the necessary measures are taken to remove these barriers and make the co-production process fully accessible to all.

Together with this, it is important to adopt a human rights understanding of disability to make it possible to establish relationships of equal partnership. This requires an understanding that people with disabilities, as citizens, have the right to participate in making decisions that affect them. Their involvement in the co-production process is important for realisation of their rights.

B. Commitment to co-production

The move towards co-production of services requires a number of changes in the way services are designed, organised and delivered. At national level, the success of the reforms depends on the top-level commitment and leadership within the government. It requires a clear vision for change, shaped by the government, with the involvement of people using services, service providers and other stakeholders. All stakeholders need to be aware of the benefits of co-production and its key principles. The European Union can also play an important role in promoting co-production by supporting research and encouraging the exchange of promising practices between Member States.

At organisational level, the commitment of senior management is equally important for embedding co-production within the organisation. The strong commitment and the clear vision of the leadership can help organisations overcome difficulties and move forward.

C. Legislation and policies supporting co-production

This recommendation has two important aspects. First, it is essential to ensure that existing legislation does not create barriers to the involvement of people with disabilities in decision-making, for example, by maintaining a system of guardianship. Under such system the legal capacity of the person is restricted or entirely taken away by a court and all important decisions (including regarding the type of support), are made on behalf of the person by a guardian. Instead, supported decision-making legislation needs to be adopted asserting the right of people with disabilities to take part in decision-making. The adoption of such legislation will place greater demands on the organisations working in the area of disability to provide advocacy support.

Second, it is important to ensure that local, regional and national legislation encourages co-production. For example, it should incorporate requirements for involvement of people with disabilities in the planning and assessment of services, promote focus on outcomes rather than activities, support user-led organisation to provide services such as peer counselling and advocacy.

D. Additive instead of substitutive co-production

Co-production requires *combining* public sector resources with the resources of people using services, which is referred to as 'additive co-production' (Löffler, n.d.). It should not be seen as a way to hand responsibility for services to the people using them and/or communities (substitutive co-production) in order to save money. People with disabilities have already been disproportionally affected by austerity measures following the financial crisis, which has resulted in cuts in social services and community-based support (ENIL, 2011). The Committee on the Rights of Persons with Disabilities (2015) has also expressed 'deep concerns' at the "disproportionately adverse and retrogressive effect" of austerity measures in the EU, restricting the rights of people with disabilities to live in the community. Policy-makers and European Union institutions should promote additive co-production in order to support the realisation of rights of people with disabilities.

E. Funding policies supporting co-production

These recommendations are particularly targeted at institutions and organisations providing funding for projects and services concerning people with disabilities. This includes public and private donors, as well as the European Union.

It is important that funding institutions and organisations have policies in place recognising and promoting the involvement of people with disabilities in a co-productive way; that is, as equal partners. At the same time, they need to ensure that these policies are implemented. For example, concerns have been raised in relation to the implementation of the partnership principle in the planning implementation and evaluation of European Structural and Investment Funds projects by Member States (ENIL, 2013).

Engagement in co-production may involve significant and long-term time commitment and participation in activities taking place in different locations, nationally or internationally. The funding rules should allow for compensation to be provided to people representing users, for their involvement in the co-productive process; related costs should also be covered.

The principles of equality, choice and control are essential for co-production. To ensure that these principles are respected, funding organisations and institutions need to involve people using services in setting the goals and the outcomes to be achieved with the funding. Goals pre-defined by the donor, even when the agreement of the person is required, limit the choice and puts pressure on the person to comply in order to use certain services.

F. Meaningful involvement of people using services

Traditional approaches to service planning and delivery disempower (and often medicalise and segregate) people with disabilities. As a result, many people may find it difficult to express and defend their views. Additional support (such as peer support and advocacy) and/or training need to be available to allow them to engage meaningfully in the design, delivery and evaluation of services. The provision of support is essential for addressing unequal power relationships between people using services and professionals, and for ensuring that they are not at a disadvantage in these relationships.

Another important factor for ensuring meaningful participation of people with disabilities is accessibility – of information and communication, physical environment, and transportation. In the context of co-production, accessibility can include providing information in accessible formats, allowing enough time for reflection and comments, ensuring that the meeting place is accessible, providing interpretation during the event and covering costs related to personal assistance. The access needs of all participants need to be taken into account and financial resources need to be allocated to cover related costs.

G. Support to and engagement of staff

Frontline staff and practitioners have a crucial role to play for effective co-production, which is often overlooked. For co-production to work in practice, staff will need to revaluate their role and relationship with people using services and move from being experts to being facilitators. Training and support should be provided to staff to make this transition, which should be based on the principles of the UN Convention on the Rights of Persons with Disabilities. There are strong arguments for the frontline staff to also be empowered and given greater autonomy and role in planning services (Social Care Institute for Excellence, 2013). The move towards co-production needs to be supported by the human resource policies of the organisation, which may need to be revised to reflect the changed roles of staff.

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